

Social Security

A Guide To Social Security
And SSI Disability Benefits
For People With HIV
Infection



www.ssa.gov

About This Booklet

Social Security can provide a lifeline of support to people with HIV infection. That lifeline comes in the form of monthly Social Security disability benefits and Supplemental Security Income (SSI) payments, Medicare and Medicaid coverage and a variety of other services available to people who receive disability benefits from Social Security.

If you are disabled because of HIV infection, this booklet will help you understand the kinds of disability benefits you might be eligible for from the Social Security or SSI programs.

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Part 1—Background Information

Acquired immunodeficiency syndrome (AIDS) is characterized by the inability of the body's natural immunity to fight infection. It is caused by a retrovirus known as human immunodeficiency virus, or HIV. Generally speaking, people with HIV infection fall into two broad categories:

1. those with symptomatic HIV infection, including AIDS; and
2. those with HIV infection but no symptoms.

Although thousands of people with HIV infection are receiving Social Security or SSI disability benefits, we believe there may be others who might be eligible for these benefits. Social Security is committed to helping all men, women and children with HIV infection learn more about the disability programs we administer. And if you qualify for benefits, we are just as committed to ensuring that you receive them as soon as possible.

You should also be aware that the Social Security Administration's criteria for evaluating HIV infection are not linked to the Center for Disease Control's (CDC) definition of AIDS. This is because the goals of the two agencies are different. The CDC defines AIDS primarily for surveillance purposes, not for the evaluation of disability.

Part 2—What Benefits Are You Eligible For?

We pay disability benefits under two programs: Social Security disability insurance, sometimes referred to as SSDI, and Supplemental Security Income, often called SSI. The medical requirements are the same for most people under both programs, and your disability is determined by the same process. However, there are major differences in the nonmedical factors, which are explained in the next two sections.

Social Security Disability Insurance Benefits: The Nonmedical Rules of Eligibility

Here are examples of how people qualify for SSDI:

- Most people qualify for Social Security disability by working, paying Social Security taxes, and in turn, earning “credits” toward eventual benefits. The maximum number of credits you can earn each year is four. The number of credits you need to qualify for disability depends on your age when you became disabled. Nobody needs more than 40 credits and younger people can qualify with as few as six credits.
- Disabled widows and widowers age 50 or older could be eligible for a disability benefit on the Social Security record of a deceased spouse.
- Disabled children age 18 or older could be eligible for dependents benefits on the Social Security record of a parent who is getting retirement or disability benefits, or on the record of a parent who has died. (The disability must have started before age 22.)
- Children under the age of 18 qualify for dependents benefits on the record of a parent who is getting retirement or disability benefits or on the record of a parent who has died, merely because they are under age 18.

For more information about Social Security disability benefits in general, ask Social Security for a copy of the booklet, *Disability* (Publication No. 05-10029).

How Much Will My Benefits Be?

How much your Social Security benefit will be depends on your earnings history. Generally, higher earnings translate into higher Social Security benefits. You can find out how much you will get by contacting Social Security and asking

for an estimate of your benefits. We'll give you a form you can use to send for a free statement that contains a record of your earnings and an estimate of your benefits.

In addition to checking your benefit estimate, we encourage you to use this statement to verify that your earnings have been properly recorded in our files. It's important that you do this because any missing or unreported wages could lower your Social Security benefit or even prevent you from qualifying for disability benefits. If you find a problem, contact your local Social Security office right away, show them proof of your actual wages, and the record will be corrected. **This can be particularly important for people who have tested positive for HIV but have not developed symptoms, so that any potential benefits will not be delayed by wage correction efforts.**

Disabled widows, widowers and children eligible for benefits as a dependent on a spouse's or parent's Social Security record receive an amount that is a percentage of the worker's Social Security benefit.

Supplemental Security Income: The Nonmedical Rules of Eligibility

SSI is a program that pays monthly benefits to people with low incomes and limited assets who are 65 or older, or blind or disabled.

Supplemental Security Income **supplements** a person's income up to a certain level that can go up every year based on increases in the cost-of-living. The level varies from one state to another, so check with your local Social Security office to find out more about SSI benefit levels in your state.

We don't count all your income when we figure out if you qualify for SSI. And if you work, there are special rules we use for counting your wages. Again, check with Social Security to find out if you can get SSI.

In addition to rules about income, people on SSI must have limited assets. Generally, individuals with assets under \$2,000, or couples with assets under \$3,000, can qualify for SSI. However, when we figure your assets, we don't count such items as your home, your car (unless it's an expensive one) and most of your personal belongings.

Your Social Security office can tell you more about the income and asset limits. For more general information, ask for a copy of the booklet, *SSI* (Publication No. 05-11000).

Part 3—How Does Social Security Define Disability?

In this section, we'll explain the criteria you must meet in order to be considered "disabled." First, we'll explain in general terms how Social Security defines and determines disability. Then we'll discuss how it applies to people with HIV infection.

The General Definition Of Disability

Disability under Social Security is based on your inability to work. You will be considered disabled if you cannot do work you did before and we decide that you cannot adjust to other work because of your medical condition(s). Your disability also must last or be expected to last for at least a year or to result in death.

For children, we decide if the condition results in marked and severe functional limitations. The condition must have lasted or be expected to last for at least 12 months or be so severe that the child is not expected to live.

How This Definition Of Disability Applies To People With HIV Infection

A person with symptomatic HIV infection is often severely limited in his or her ability to work. In other words, if the evidence shows that you have symptomatic HIV infection that severely limits your ability to work, and if you meet the other eligibility factors, the chances are very good that you will be able to receive Social Security or SSI benefits.

On the other hand, some people with HIV infection may be less impaired and able to work, so they may not be eligible for disability.

Part 4—How Does Social Security Evaluate Your Disability?

Social Security works with an agency in each state, usually called a Disability Determination Service (DDS), to evaluate disability claims. DDS staff follow a process that applies to all disability claims. It's a step-by-step process involving five questions. They are:

Step 1—**Are you working?**

If you are and your earnings average more than \$800 a month, you generally cannot be considered disabled. If you are not working, we go to the next step.

Step 2—**Is your condition “severe”?**

Your condition must interfere with basic work-related activities for your claim to be considered. If it does not, we will find that you are not disabled. If it does, we will go to the next step.

Step 3—**Is your condition found in the list of disabling impairments?**

For each of the major body systems, we maintain a list of impairments that are so severe they automatically mean you are disabled. If your condition is not on the list, we have to decide if it is of equal severity to an impairment that is on the list. If it is, we will find that you are disabled. If it is not, we go to the next step.

Note: There is a complete list of impairments for HIV infections. This list includes many conditions associated with symptomatic HIV infection, including some that apply specifically to women and children with HIV infection. (See Pages 10-12.)

Some of the HIV-related conditions included in the HIV list of impairments are shown below.

- Pulmonary tuberculosis resistant to treatment
- Pulmonary tuberculosis resistant to treatment
- Kaposi's sarcoma
- Pneumocystis carinii pneumonia (PCP)
- Carcinoma of the cervix
- Herpes Simplex
- Hodgkin's disease and all lymphomas
- HIV Wasting Syndrome
- Syphilis and Neurosyphilis
- Candidiasis
- Histoplasmosis

Remember: These are just a few examples. You can see a complete list of HIV-related impairments at any Social Security office.

Step 1—**Can you do the work you did previously?**

If your condition is severe, but not at the same or equal severity as an impairment on the list, then we must determine if it interferes with your ability

to do the work you did previously. If it does not, your claim will be denied. If it does, we go to the next step.

Step 2—**Can you do any other type of work?**

If you cannot do the work you did in the past, we see if you are able to adjust to other work. We consider your medical conditions and your age, education, past work experience and any transferable skills you may have. If you cannot adjust to other work, your claim will be approved. If you can, your claim will be denied.

Remember, at all steps in the process, your impairment must be documented. Documentation includes medical records from your doctors, as well as laboratory test results, X-ray reports, etc. The HIV infection itself—that is, the presence of the virus—must be documented as well as any HIV-related manifestations. It is important that we have evidence of signs, symptoms and laboratory findings associated with HIV infection, as well as information on how well you are able to function day-to-day. The signs and symptoms may include: repeated infections; fevers/night sweats; enlarged lymph nodes, liver or spleen; lower energy or generalized weakness; dyspnea on exertion; persistent cough; depression/anxiety; headache; anorexia; nausea and vomiting; and side effects of medication and/or treatment, as well as how your treatment affects your daily activities.

Evaluation Of HIV Infection In Women

Statistics show that there is an increasing number of women with HIV diseases. Social Security's guidelines for the immune system recognize that HIV infection can show up differently in women than in men. In addition to following the criteria outlined in the previous section, DDS disability evaluators consider specific criteria for diseases common in women. These include: vulvovaginal candidia-

sis (yeast infection); genital herpes; pelvic inflammatory disease; invasive cervical cancer; genital ulcerative disease; and condyloma (genital warts caused by the human papillavirus). The list of impairments describes the level of severity necessary for these impairments to be considered disabling.

Evaluation Of HIV Infection In Children

We have separate listings for children with HIV infection. These guidelines recognize that the course of the disease in children can differ from adults. In order to be found disabled, a child must have a condition that exactly matches or is equal in severity to either the adult or childhood HIV listing or another impairment found in the list of impairments.

For more information about disability benefits for children, ask Social Security for a copy of the booklet, *Social Security And SSI Benefits For Children With Disabilities* (Publication No. 05-10026).

Part 5—How Do You File For Disability Benefits?

You apply for Social Security and SSI disability benefits by calling or visiting any Social Security office. All Social Security files are kept strictly confidential. It would help if you have certain documents with you when you apply. But don't delay filing because you don't have all the information you need. We'll help you get the rest of it after you sign up. The information you'll need may include:

- your Social Security number and birth certificate;
- the Social Security numbers and birth certificates for family members signing up on your record; and

- a copy of your most recent W-2 form (or your tax return if you're self-employed).

If you're signing up for SSI, you will need to provide records that show that your income and assets are below the SSI limits. This might include such things as bank statements, rent receipts, car registration, etc.

You'll also need to give us information about how your condition affects your daily activities, the names and addresses of your doctors and clinics where you've received treatment and a summary of the kind of work you've done in the past. If you have medical evidence such as reports of blood tests, laboratory work or a physical, it would be helpful if you brought them with you. On the following pages, we give you some guidelines for providing us with medical and vocational information that will help speed up your claim. But first we want you to know what Social Security does to make the process work as smoothly as possible.

What Steps Has Social Security Taken To Ensure Prompt Processing And Payment Of Disability Benefits?

All HIV infection claims receive prompt attention and priority handling. For many people applying for SSI with a medical diagnosis of symptomatic HIV infection, the law allows us to **presume** they are disabled. This permits us to pay up to six months of benefits pending a final decision on the claim. You will qualify for this immediate payment if:

- a medical source confirms that the HIV infection is severe enough to meet Social Security's criteria;
- you meet the other SSI nonmedical eligibility requirements; and
- you are not doing "substantial" work, i.e. your earnings are under \$800 per month (see Page 8).

If you have symptomatic HIV infection but the local Social Security office cannot provide immediate payment, a disability evaluation specialist at the DDS may still make a “presumptive” disability decision at any point in the process where the evidence suggests a high likelihood that your claim will be approved. (If we later decide you are not disabled, you will **not** have to pay back the money you received.)

We have made special arrangements with a number of AIDS service organizations, advocacy groups and medical facilities to help us get the evidence we need to streamline the claims process. And many DDS’s have Medical/ Professional Relations Officers who work directly with these organizations to make this process work smoothly.

What You Can Do To Expedite The Processing Of Your Claim

You can play an active and important role to ensure that your claim is processed accurately and quickly. The best advice we can give you is to keep thorough records that document the symptoms of your illness and how it affects your daily activities, and then to provide all of this information to Social Security when you file your claim. Here are some guidelines you can follow:

- **Document the symptoms of your illness early and often**
Use a calendar to jot down brief notes about how you feel on each day. Record any of your usual activities you could not do on any given day. Be specific. And don’t forget to include any psychological or mental problems.
- **Help your doctor help you** Not all doctors may be aware of all the kinds of information we need to document your disability. Ask your doctor or other health care professional to track the course of your symptoms in detail over time and to keep a thorough record of any evidence

of fatigue, depression, forgetfulness, dizziness and other hard-to-document symptoms.

- **Keep records of how your illness affected you on the job**
If you were working, but lost your job because of your illness, make notes that describe what it is about your condition that forced you to stop working.
- **Give us copies of all these records when you file**
In addition to these records, be sure to list the names, addresses and phone numbers of all the doctors, clinics and hospitals you have been to since your illness began. Include your patient or treatment identification number if you know it. Also include the names, addresses and phone numbers of any other people who have information about your illness.

Part 6—Helping You Return To Work

If you return to work, Social Security has a number of special rules, called “work incentives,” that provide cash benefits and continued Medicare or Medicaid coverage while you work. They are particularly important to people with HIV disease who, because of the recurrent nature of HIV-related illnesses, may be able to return to work following periods of disability.

The rules are different for Social Security and SSI beneficiaries. For people getting Social Security disability benefits, they include a nine-month “trial work period” during which earnings, no matter how much, will not affect benefit payments; and a three-year guarantee that, if benefits have stopped because a person remains employed after the trial work period, a Social Security check will be paid for any month that earnings are below the “substantial” level (generally \$800). In addition, Medicare coverage extends through the three-year timeframe after the trial work period, even if your earnings are substantial.

SSI work incentives include continuation of Medicaid coverage even if earnings are too high for SSI payments to be made, help with setting up a “plan to achieve self-support” (PASS), and special consideration for pay received in a sheltered workshop so that SSI benefits may continue even though the earnings might normally prevent payments.

The Ticket to Work and Work Incentives Improvement Act of 1999 substantially expands opportunities for people with disabilities who want to work.

- The law extends Part A premium-free Medicare coverage for seven years and nine months for Social Security disability beneficiaries who work, four-and-a-half years beyond the previous 39 months of extended coverage.
- States may now provide Medicaid coverage to people who are not yet too disabled to work and who have incomes above 250 percent of the federal poverty level.
- Starting early in 2001, Social Security and SSI beneficiaries may receive a “ticket” they may use to obtain vocational and rehabilitation and other employment support services from an approved provider of their choice. An individual using a ticket will not need to undergo the regularly scheduled disability reviews. The program will be phased in nationally over a three-year period.
- Also as of January 1, 2001, when a person’s Social Security or SSI disability benefits have ended because of earnings from work, he or she can now request reinstatement of benefits without filing a new application.

These and other work incentives are explained in detail in the publication, *Working While Disabled... How We Can Help* (Publication No. 05-10095). For a free copy, just call or visit your nearest Social Security office.

Part 7—What You Need To Know About Medicaid and Medicare

Medicaid and Medicare are our country's two major government-run health insurance programs. Generally, people on SSI and other people with low incomes qualify for Medicaid, while Medicare coverage is earned by working in jobs covered by Social Security, for a railroad or for the federal government. Many people qualify for both Medicare and Medicaid.

Medicaid Coverage

In most states, Social Security's decision that you are eligible for SSI also makes you eligible for Medicaid coverage. (Check with your local Social Security or Medicaid office to verify the requirements in your state.)

State Medicaid programs are required to cover certain services, including inpatient and outpatient hospital care and physician services. States have the option to include other services, such as intermediate care, hospice care, private duty nursing and prescribed drugs.

For more information about Medicaid, contact your local Medicaid agency.

Medicare Coverage

If you get Social Security disability, you will qualify for Medicare coverage 24 months after the month you became entitled to those benefits. Medicare helps pay for:

- inpatient and outpatient hospital care;
- doctors' services;
- diagnostic tests;
- skilled nursing care;

- home health visits;
- hospice care; and
- other medical services.

For more information about Medicare, call or visit your local Social Security office to ask for the booklet, *Medicare* (Publication No. 05-10043).

Help For Low-Income Medicare Beneficiaries

If you get Medicare and have low income and few resources, your state may pay your Medicare premiums and, in some cases, other “out-of-pocket” Medicare expenses such as deductibles and coinsurance. Only your state can decide if you qualify. To find out if you do, contact your state or local welfare office or Medicaid agency. For more general information about the program, contact Social Security and ask for the leaflet, *Medicare Savings For Qualified Beneficiaries* (HCFA Publication No. 02184).

For More Information

Visit our Internet Website

If you have a computer and can access the Internet, check out Social Security Online, our Internet website at www.ssa.gov for a variety of information and services, including:

- Publications you can download on all aspects of Social Security programs
- Forms you can use to request various services, such as a *Social Security Statement*, a replacement Social Security or Medicare card, or benefit verification

- *Social Security eNews*, an electronic newsletter that you can receive by e-mail free-of-charge to help you keep up with the latest changes in Social Security programs
- A Retirement Planner, designed to help people of all ages plan their future financial security using their Social Security benefits as a base

If you don't have a personal computer, many libraries and other nonprofit organizations provide Internet access services to the public. Call your local library for more information.

Call our 800 Number

You can get recorded information 24 hours a day, including weekends and holidays, by calling our toll-free number, **1-800-772-1213**. You can speak to a service representative between the hours of 7 a.m. and 7 p.m. on business days. Our lines are busiest early in the week and early in the month, so, if your business can wait, it's best to call at other times. Have your Social Security number handy when you call.

People who are deaf or hard of hearing may call our toll-free TTY number, 1-800-325-0778, between 7 a.m. and 7 p.m. on business days.

We treat all calls confidentially—whether they're made to our toll-free numbers or to one of our local offices. We also want to ensure that you receive accurate and courteous service. That is why we have a second Social Security representative monitor some incoming and outgoing telephone calls.

NOTES

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